NETWORK NEWS

News from the Utah Birth Defect Network

http://health.utah.gov/birthdefect

January is Birth Defect Prevention Month

In Utah 1,400 babies are born with birth defects every year. Birth defects are the leading cause of infant deaths. The Utah Birth Defect Network is concerned that many women do not know what they can do to increase their chances of having a healthy baby. Recognizing the important role folic acid plays in the prevention of serious birth defects, January has been proclaimed Birth Defect Prevention Month.

While the causes of most birth defects are not known, there are a number of ways a woman can reduce her risk of having a baby with a birth defect. One important way simply involves taking a multivitamin containing folic acid.

Studies show that taking the B vitamin, folic acid, before pregnancy decreases the risk of having a pregnancy affected with a neural tube defect (NTD) by at least 50 percent. The two most common NTDs are spina bifida and anencephaly. NTDs occur very early in pregnancy, 15 to 30 days after conception, which would be before a women even knows she is pregnant.

The U.S. Public Health Services recommends that all women between 15 and 44 years of age consume 400 micrograms (400 mcg or 0.4 mg) of synthetic folic acid each day. Women should begin taking a multivitamin with folic acid at least three months before getting pregnant. Since about half of all pregnancies are unplanned, it is important that all women of childbearing years take a multivitamin with folic acid every day whether they plan to get pregnant or not.

In addition to taking a multivitamin with folic acid, women should eat a healthy diet. Certain breakfast cereals are now fortified with synthetic folic acid, as are enriched grains and pastas. However, it still may be difficult to get adequate amounts of folic acid by diet alone. Most over-the-counter multivitamins contain the necessary amount of folic acid. The label should state 'USP' which means the vitamins have been tested for dissolution and absorption.

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC was established to prevent birth defects and developmental disabilities, promote optimal child development, and protect the health and welfare of Americans affected with birth defects and disabilities. As part of the NCBDDD, nine Centers, including Utah are involved in conducting the largest case-control study of birth defects. This study will dramatically increase our understanding of the causes of birth defects and will provide information for developing effective programs to prevent birth defects.

Inside this issue:

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Update on UBDN Surveillance

Over the past year, Utah Birth Defect Network (UBDN) surveillance staff worked with 22 birth hospitals in the state to bring them into compliance with Utah's Birth Defects Reporting Rule, R398-5. This rule establishes reporting requirements for birth defects in Utah and for birth defect-related test results.

We would like to thank all Health Information Management (HIM) Directors and their staff involved in this effort for their cooperation and assistance. As of August 1, 2004, all 22 hospitals have provided the UBDN with a 2003 discharge report of birth defect cases and will continue reporting henceforth on a monthly basis. The UBDN now has 100% compliance with the Birth Defects Reporting Rule from Utah birth hospitals.

From the 2003 discharge reports, 147 new *potential* birth defect cases previously unreported to the UBDN were identified. It is anticipated that fewer than 5% of these 2003 cases will be determined *true* cases after investigation and clinical case review; the small numbers will likely not change Utah's defect-specific 2003 prevalence rates.

For public health monitoring programs such as the UBDN, the over-reporting of cases—that is, identifying potential cases that turn out to be false positives—is an expected and accepted consequence of trying to achieve as close to 100% of reporting as possible. An unanticipated benefit of bringing all hospitals into reporting compliance is that new *potential* cases identified at birth are reported quickly to the UBDN, thus improving the timeliness of surveillance activities.

UBDN surveillance staff was invited to present at the Utah Department of Health's Office of Vital Records and Statistics (OVRS) fall 2004 regional meetings held throughout the state with birth certificate clerks and their supervisors. The focus of UBDN's presentation was to compare the completeness of reporting of birth defects on Utah birth certificates to the UBDN for the years 1999-2002. Four specific birth defects were evaluated, corresponding to what the scientific literature refers to as physically "obvious" (e.g., neural tube defects and oral facial clefts) and "subtle" birth defects (e.g., congenital heart defects and craniosynostosis). Congruent with literature, physically obvious defects are more likely than non-physical defects to be picked up at the time of birth. However, even physically obvious defects were not identified 100% of the time on birth certificates, supporting the need to have multiple sources involved in reporting potential birth defect cases to the UBDN.

WIC Vitamin Project

In 2000, the Utah Birth Defect Network evaluated the demographics of women who had given birth or had a pregnancy affected with a neural tube defect. The majority of NTDs between 1994 and 2000 occurred in women under 30 years of age in the 2nd or greater pregnancy. Based on this information, the largest population of women in their childbearing years that would permit intervention and evaluation were non-pregnant women enrolled in WIC. A grant was obtained through the Utah Chapter of the March of Dimes with matched funds through Medicaid to purchase over 8,000 bottles of multivitamins with folic acid. The UBDN director met with WIC directors to educate them on the project. Individual WIC clinic staff were trained for the one-on-one folic acid education of all non-pregnant WIC clients. Multivitamins were distributed in December 2000 and throughout 2001 as needed by each clinic.

This project has been so successful that funding to purchase additional multivitamins was obtained in 2002 and again in 2003.

The WIC Client Satisfaction Survey completed in the summer of 2001 randomly surveyed WIC clients. The majority of WIC clients were between the ages of 19-33 years (71%), with an average age of 27 years. Approximately 71% were married, 62% were white and 36% were Hispanic. Of those women who participated in this educational campaign, 88% stated that they took the multivitamins: of those, 45% took part of the bottle of multivitamins; 42% finished the bottle; and 12% finished the first bottle and obtained a second bottle of multivitamins. Of the 12% of women who did not take any multivitamins, the majority (49.1%) forgot; 20.7% stated that the vitamins made them sick. Other frequent reasons for not taking the free multivitamins included "I didn't think I would get pregnant"; "I thought I would gain weight"; "I get my vitamins from food".

Behavioral Risk Factor Surveillance System (BRFSS) data from 1999 to 2002 demonstrates an increase in the number of women who *were aware* of folic acid, from 79.4% to 85.5%. Additionally, women's *knowledge* that folic acid prevents birth defects increased from 44.6% to 59.2% during this same time period. This information tells us that our message is getting out to the public and they are changing their behaviors.

Despite continuous efforts in educating consumers and health care providers there is still work to be accomplished. Awareness about folic acid and knowledge that a multivitamin with folic acid can prevent some birth defects are the first steps to have women change their behavior. The WIC project and the BRFSS data strongly suggest that women will change their behavior if this folic acid message is directly received and discussed with their health care provider or clinic staff.

Neural Tube Defects in Utah

Neural tube defects refer to a group of birth defects when the early precursors to the brain or spinal cord, fail to properly form. The two most common NTDs are anencephaly and meningomyelocele (spina bifida). Other rarer NTDs include encephalocele, lipomeningomyelocele, and rachischisis defects. Anencephaly is always fatal, whereas spina bifida may cause severe disabilities for the child. These birth defects occur early in a pregnancy, between 15 and 30 days after conception, before a woman knows that she is pregnant.

One of the greatest public health success stories is the discovery that the water soluble B vitamin, folic acid, when taken prior to pregnancy, will reduce the likelihood of having a child affected with an NTD. Since 1998, all fortified cereal grains in the United States are required to contain folic acid. The UBDN documented the change in prevalence of neural tube defects in Utah before and following the 1998 requirement for folic acid fortification as depicted in the graph below. Utah has demonstrated a decrease in NTD prevalence over the past ten years.

UBDN is leading the Utah Folic Acid Coalition, which continues to educate all women of reproductive age to consume a multivitamin with 400 micrograms (0.4 milligrams) of folic acid daily *in addition* to eating a healthy diet (MMWR, 1992).

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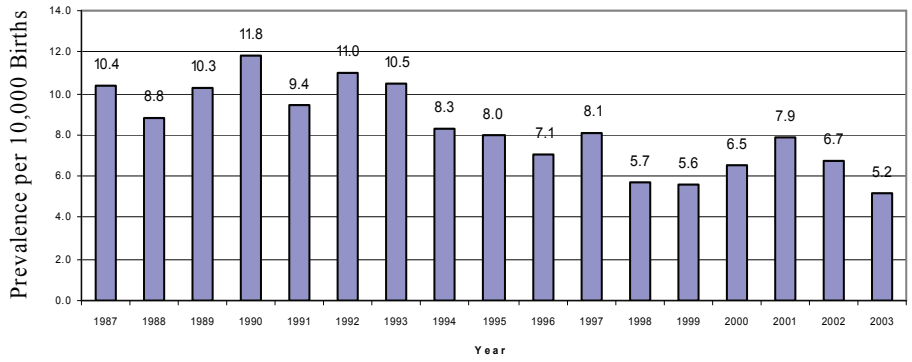
Prevalence of Neural Tube Defects in Utah, 1985-2003



From the Outreach Desk

The Utah Birth Defect Network (UBDN) is the main participant of the Utah Folic Acid Council, working to increase education, awareness, and consumption of folic acid among women of childbearing age. The purpose of this campaign is to prevent the occurrence and recurrence of neural tube defects. ***Since 1992, NTDs have decreased approximately 50% in Utah.*** While this decrease demonstrates a success, education for women in their childbearing years still must continue. Utah health care providers play a key role in educating women and families. More women need to consume a daily multivitamin with folic acid, whether or not they are planning a pregnancy. Utah data demonstrate that women are more likely to take a multivitamin supplement with folic acid ***if advised to do so by their health care provider.***

Prevention efforts offer hope for reducing the number of families in Utah affected by birth defects. The UBDN, in conjunction with the Utah Department of Health, recommends the following prevention strategies, which can easily be incorporated into a health care provider's practice:

- *Provide folic acid education as a standard of care. The U.S. Public Health Service recommends that all women of childbearing age consume 400 micrograms (400 mcg or 0.4 mg) of folic acid every day to prevent up to 70% of neural tube defects in the U.S.*
- *Counsel patients to plan their pregnancies and to reduce or eliminate high-risk behaviors (alcohol, tobacco, and drug use) that lead to poor birth outcomes.*

You can make a difference in the lives of Utah families! The UBDN has information about birth defects prevention. Please take advantage of this opportunity to give your female patients up-to-date information about how to prevent birth defects. Should you have questions, please call 801-257-0566 ext 204 or email aenance@utah.gov.

Amy Nance, B.S.

Project Coordinator

National Folic Acid Awareness Week

January 24-30, 2005

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